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ABSTRACT

Cortical blindness is defined and its diagnosis is explained. Guidelines and sample activities are presented for use in a cognitive/visual/multi-sensory stimulation program to produce progress in cortically blind infants. The importance of using the eyes from birth through early development in order to form the nerve pathways responsible for visual perception is stressed. It is also emphasized that a child's visual skills can never be greater than his or her overall mental ability. In order for progress to be made in visual stimulation, three elements are necessary: a capacity for memory, a way for the child to signal a definite response, and motivation. General guidelines are offered to teachers and parents to develop infant visual skills in the areas of awareness and fixation, following and tracking, and cognitive/visual skills. Cognitive/visual skills involve recognition of familiar people, things, and events; anticipation of routine events; development of behaviors that produce changes in the child's environment; and memory for things and people not present. Includes 16 references. (JDD)

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THE CORTICALLY BLIND INFANT

Educational Guidelines and Suggestions

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November 11, 1987

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THE CORTICALLY BLIND INFANT

Educational Guidelines and Suggestions

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What is cortical blindness?

Cortical blindness is defined as a loss of vision because of an abnormality of the visual cortex of the brain, a loss which can range from severe visual impairment to total blindness (Jose and Stavis 1987). It is a term that means the brain is not understanding or interpreting what the eye sees. Although we think we see with our eyes, we really see with our brain. The eyes just send the picture to the brain. For example, you know a chair when you see one because of your past experience with chairs. In early infancy you learned the feel and function of chairs, and remembered what chairs look like. True cortical blindness means that the parts of the brain which remember and understand what you see are not working.

Usually a parent or other caregiver suspects that a child has a vision problem before the age of one year. The baby may not look at them and smile, or does not show interest in any toys.

When an ophthalmologist (eye doctor) examines a child and diagnoses cortical blindness, the doctor may not find anything wrong with the eyes themselves. The diagnosis implies that there is some form of brain damage, or brain malformation. It can be a temporary or permanent condition. Often it is found as a diagnosis in children who are severely multi-handicapped. Cortical blindness can be the result of accidental injury to the brain through trauma, disease, or tumor. It may or may not necessarily be associated with other handicapping conditions. In most cases of cortical blindness diagnosed before the age of 1 year, the infant will most likely have other serious impairments as well.

Certain other conditions are sometimes diagnosed in conjunction with the diagnosis of cortical blindness. **Optic nerve hypoplasia** is the failure of the optic nerve (which connects the eye to the brain) to develop to its full size. It can affect vision depending on its severity. Optic atrophy, or **optic nerve atrophy**, is a condition in which there is evidence that the optic nerve head (where it enters the back of the eyeball) has suffered some damage or degeneration. Quite often this is seen in children with cerebral palsy.

More effort is being made by ophthalmologists to make the diagnosis of cortical blindness more exact in its meaning (Jose and Stavis). This approach would mean that all other eye conditions would have to be ruled out before the diagnosis of cortical blindness could be accurately given.

It is generally believed that a normal child (beyond the age of infancy) who suffers brain damage through accident or illness and consequently becomes cortically blind, has some chance (depending upon the amount of damage) of recovering some visual skills during a period of up to 3 years after the injury. The brain does its best to repair and rechannel the damaged "wiring" so to speak.

But how much vision the child ultimately recovers depends upon 1) the severity of the brain damage, and 2) the opportunities a child is given to learn or re-learn how to see.

The guidelines and the example activities outlined below might produce some amount of progress in a cortically blind infant. It is a cognitive/visual/multi-sensory stimulation approach which can be used by parents, caregivers, and teachers of multi-handicapped infants. These activities should not be considered the sole domain of a teacher of the visually handicapped. Severely impaired children require daily consistency in programming, a situation which does not easily lend itself to the itinerant services of a teacher of the visually impaired. Cortical blindness requires a cognitively based approach since we are dealing with memory and the interpretation of the visual world.

Unfortunately, there is no hard research which proves that visual stimulation produces progress in severely and profoundly handicapped children (Erin 1986). However, no one can absolutely predict the benefits to any particular child.

The main body of research that has been cited by supporters of visual stimulation is that of animal sight deprivation. Researchers Hubel and Weisel (1970) showed that if newborn kittens were not allowed to use their vision by virtue of having their eyelids surgically sewn shut, when the lids were later re-opened as adults, they were functionally blind. Without visual input, the brain structures responsible for visual processing failed to develop properly. In effect, the cats were cortically blind. Research with human infant visual preferences shows that infants under 6 months of age search out visually interesting things to gaze upon. Many researchers feel this is how the infant begins the neurological process of developing the brain and cognitive structures required for seeing.

The research mentioned above dealt with animals or infants who were neurologically intact. The impact of stimulation on a severely damaged nervous system is not as easily researched due to the extreme complexity of the brain. What is known is that using the eyes from birth through early development is critical for the formation of certain nerve pathways responsible for visual perception.

Ophthalmologists have noticed that in certain cases of slow visual development, in which the label cortically blind may have been applied, an infant is simply slow in the myelinization of the optic nerve pathways (Hoyt 1982). Myelinization is the process by which a nerve develops an exterior coating so that it can transmit nerve impulses properly. In cases such as this, the infant may be somewhat over a year old before expected visual responses are present. Ophthalmologists are now beginning to use a more descriptive diagnosis in this instance, namely, severe visual developmental delay or cortical visual impairment (Jose and Stavis 1987).

Another known fact is that infants who are born with limited vision due to defects of the eye, and who have no brain damage, can learn to use what vision they have more efficiently as they get older (Barraga 1964). It is very important that they be motivated to use what vision they have.

An important factor to keep in mind, lest someone be given false hope by reading these pages, is that **a child's visual skills can never be greater than his or her overall mental ability** (Barraga 1983). For example, if a profoundly handicapped 4 year old's overall intellectual functioning is at a 2 month old level, then his or her visual skills would not exceed that of a 2 month old.

"Learn how to see."

As young infants, we all had to learn how to see. When you see a fast approaching object you will probably blink and duck, or protect yourself with your hand. An infant under the age of 3 months will not know that a fast approaching object is a danger. The baby learns this through experience.

Young infants soon begin to show signs of having a memory (Shephard and Fagan). They remember and recognize their parents faces, what their bottle looks like, and their favorite toys. We know they recognize these things because of their reactions. They smile when they see their parents, they show excited movements when they see the bottle approaching, or hear the bell on the microwave oven signaling that warm milk will soon be at hand. They might suddenly get quiet as if paying attention, or turn their head and eyes to follow a person or favorite toy. Even totally blind infants under 1 year old, if they have no intellectual handicaps, show a memory for familiar people and their voices, or the sounds of favorite toys or activities. **A capacity for memory**, for people, events, and things that are seen, felt, and heard, **is absolutely crucial if any progress is to be made in visual stimulation.**

Besides a capacity for memory, another crucial ability that will make educational programming possible is whether the child has any way to signal a definite response. Popular technology now makes it possible for a child to simply make a small movement of any part of the body to activate a switch which can be attached to a toy, or a communication device. The crucial element here is whether the child can be trained to give consistent and purposeful responses. In this way, even a child with no speech can indicate a yes or no answer, or make choices from a display of objects or words to communicate his or her needs.

A non-handicapped infant progresses through the stages of learning to use vision so quickly that we take it for granted. A handicapped infant may develop visual skills more slowly. If you become aware of the various skills, you can make some adaptations which might help your child use his or her vision.

Brain damage or profound retardation can prevent a child from progressing cognitively and visually. However, you can start with some of the ideas below to see if some progress is possible. Professionals are not sure how much or how little vision your child will be able to use in the 1 to 3 year period after the cause of the cortical blindness. Each child is different, so you might want to try some of the activities listed.

Motivation is a major part of encouraging an infant or young child to use his or her vision. Your job is to discover the kinds of things your child enjoys doing with you, so that you can playfully fit them into your daily routine.

VISUAL SKILL AREAS

Infant visual skills fall into these broad catagories. There are other more detailed sources of information about visual skills listed in the references. Each area will be discussed below in the ACTIVITIES section.

I. General Guidelines
II. Awareness and Fixation
III. Following and Tracking (with note of precaution for blacklights)
IV. Cognitive/Visual Skills
    A. Recognition of familiar things, people, and events
    B. Anticipation of familiar routines
    C. The infant's development of behaviors that produce changes in his or her environment
    D. Memory for things and people not present

Explained below are some suggested activities given as examples only of many possible ones. You must use your imagination. The ultimate hope is that the severely handicapped, cortically blind infant will develop a memory and a way to signal that (s)he is aware of her/his surroundings and can communicate that awareness.

ACTIVITIES

I. GENERAL GUIDELINES FOR TEACHERS

Keep these things in mind when you are asking a cortically blind infant to look at the visual targets (people or things) mentioned in the activities.

a. Use bright illumination unless child reacts negatively. Watch for glare. Rearrange child or light source. Try to have the light source above and behind the child.

b. Do not shine lights into a child's eyes.

c. Eliminate confusing backgrounds by putting visual item against a plain background of contrasting color (dark on light or vice versa).

d. When working on choice-making, start with only one item. When accomplished, gradually add in two or three choices.

e. Do not over-stimulate the child. If child reacts negatively by closing the eyes crying or having seizures, stop what you are doing and reduce the amount of stimulation. Ask an occupational therapist trained in the use of sensory stimulation to assist you. Teamwork always helps.

f. The sense of touch reinforces and adds to the visual perception and memory of something you want the child to see. Always follow visual presentation with tactile presentation.

A famous experiment by R. Held and A. Hein in 1963 showed that tactile stimuation and movement were essential to visual perception (Gregory 1966). They raised kittens in total darkness, except for the experimental situation in which they were permitted to use their vision. Each kitten was allowed to move in a circle while being suspended in a basket. The first kitten's feet were able to touch the floor to produce walking movements, while the second was simply passively carried in an identical basket. Only the active kitten developed visual perception. The passive one remained effectively blind. **The sense of touch adds meaning to what is visually perceived.**

II. AWARENESS AND FIXATION: Suggestions to Parents

If your infant is not following the movement of people and objects with eyes and head turn, (s)he may need to spend time with fixating and focusing activities. You can make the play area, the crib, and the changing table places where your baby can exercize his looking. Fixating generally means looking steadily at something for seconds at a time.

Research in infant visual preferences (Sheperd and Fagan) shows they enjoy looking at the following things:

1. **Patterns:** Try bold designs in black and white, or any dark on light contrast, such as red on white, or purple on yellow. Using a felt tip marker, you can draw bulls-eyes, checkerboards, faces, stripes, polka dots, and curved lines. Draw or glue these on the bottom of sturdy paper plates, put something inside that makes noise, glue them together around the edges, and hang within baby's reach in the play area. High contrast designs on fabric can decorate crib bumpers, quilts, even a smock, shirt, or apron. See if your baby has more interest in a particular color.

Watch your baby's eyes to see if she opens them wider. Also look for changes in overall body movements as a sign that he is paying attention to something visual. Be careful not to over-stimulate a child with a damaged nervous system. If your infant turns away, shuts her eyes, or cries, discontinue the stimulation. Reduce the brightness of the colors, and the amount of time spent looking at them. You might want to consult a teacher or occupational therapist.

2. **Faces:** Your very own face is probably the most enjoyable thing your baby would want to gaze upon. Infants are programmed, so to speak, to enjoy people's faces. It's a good survival skill, as well as a way to create emotional bonding. So spend time in front of your child talking and laughing while placing your child's hands on your face. Remember this important point throughout: **touch reinforces vision.**

To get visual regard of your face, you can also use a flashlight as a spotlight on your face in a dim or dark room. Never shine a flashlight into your child's eyes. He may not have full use of the eye's normal way of blocking out too much light by constriction of the pupils.

3. **Favorite toys:** Infants love to look at their favorite toys. They usually prefer brightly colored things, red, blue, orange, or black and white (get a panda bear). Try to get several seconds of interest with favorite toys. Variety is the key to interest and motivation. Also remember, toys that make sound, especially if the child can cause the sound himself, will more easily attract the visual attention. Bring your child's hands up

to the toy, because touch reinforces vision!

Always use sound and touch to help your child be interested in looking.

III. FOLLOWING AND TRACKING: Suggestions to Parents

The visual skill of following is a term that describes how the child fixates or stares at something, then moves both the eyes and the head to keep up with the visual target when it begins to move. Tracking involves using the eyes alone without head movement.

Most infants under 4 months old have jerky following, rather than smooth. They also will follow with just one eye or the other since they have not yet developed the skill of using both eyes together in a coordinated way (binocular vision). As you encourage your infant to follow, use the motivating things mentioned under the fixation section, but move them very slowly at first. Start slightly to the right or left of midline and move toward the midline. It has been reported that cortically involved children have better peripheral vision (Langley 1980). Horizontal motion is easier than vertical motion for a beginner to follow.

While seeing the development of following or tracking in a child, when there was none before,is quite thrilling, one must understand the following somber thought. **Visual following can be done on an unconscious level.** In fact it can occur in children who have very damaged visual cortexes, or who are diagnosed as anencephalic (born with a brain stem, but no cortex). **It is not as important to work on tracking as it is to work on getting visual recognition.** Tracking is an important skill. However, children with relatively poor tracking skills, who have the ability to recognize (memory) and respond (signal), can still benefit from some educational (cognitive) programming.

The best things to use for tracking are those things mentioned in the section on fixation. Use anything or anyone the child enjoys looking at, such as favorite pets, brothers or sisters, etc.

FLOURESCENT BLACKLIGHT

Since the early 1980's, doing what is called visual stimulation using flourescent blacklight has gained popularity with some parents and professionals. Use of the light in a dark room to make objects in flourescent colors stand out against a dark background has the effect of shutting out distracting visual background (Potenski 1983). Sometimes this effect allows a child to put his or her attention solely on the visual target. Occasionally the use of the blacklight can produce a visual response in a severely handicapped child where there was none using normal room light.

Anyone using blacklight should be aware of the following points:

A) **The use of blacklight is controversial due to some scientific research which shows that ultraviolet light can have injurious effects on the health of the eye over long term exposure** (Knowlton, 1986). Proper precautions involve :

-making sure the light is behind the child

-neither child nor caregiver look at the light directly

-limit time of exposure to 10 minutes

-consider use of spectacles which are treated to screen out ultraviolet wavelengths

-wean the child off use of blacklight by gradual increase of room light.

For short periods, a 15 watt blacklight tube should not be any hazard to a child's eyes when used properly as outlined above. such that the light reflecting off the toys has been changed to some part of the visible spectrum. A random glance will not cause any eye problems so far as is known (Tredici 1982).

B) "Visual stimulation" given apart from the meaningful events in a child's daily life will not produce in the child's mind the recognition of visual events. Recognition is tied to repetition in a meaningful flow of daily life, whereby the child attaches meaning to what she or he perceives visually, auditorially, or tactually.

> *No learning experience is any more valuable than its real application to the child's life....Visual stimulation is more than a flashlight because it is done to enhance the efficiency of perceptual skills used in learning and living (Harrell and Akeson 1987).*

IV. COGNITIVE/VISUAL SKILLS : Suggestions to Parents

A. Recognition of familiar people, things, and events

The activities of daily life are the most appropriate experiences for allowing a cortically blind infant to learn. Here are some examples. Do these things consistently as often as each situation or event occurs.

1. You and other people very familiar to your child are already doing this one, namely: spend time in front of your child talking, touching, and letting him look at you. If you want to see if he knows you visually, appear in front of him and smile without talking. Does he respond? If he does not respond visually, try your voice. Do you get a smile or some other consistent signal that he recognizes you? Bring in someone he does not know well and compare his response to that person. How does he act as you hold him compared to when a stranger holds him?

2. Before you give your child that next bottle, cup of juice, or spoonful of food, pause and make sure you show it to her first. In playful ways tell her, "here comes your bottle," (or cup, or the spoon, etc.). You might try holding it just slightly right or left of center, since many children with cortical blindness have slightly better vision in those areas (Langley 1980). Try to make it a habit to use the **LOOK BEFORE YOU GET** approach. Of course, after she looks, let her touch it or hold it, to reinforce the visual meaning.

B. ANTICIPATION OF ROUTINE EVENTS

Before any routine event, such as getting ready to ride in the car, getting ready for bath, getting a dry diaper, mealtine, bedtime, choose some item that you always show her, and let her touch and hold. This item should be a part of the activity, such as: the car keys, the washrag (a bright color), the soap, the diaper, the bib (a bright color), a favorite bedtime toy. Do this often to try to build up an association in your child's mind between the item and the upcoming activity. **LOOK FOR EXPRESSIONS OF ANTICIPATION,** such as excited movements, smiles and vocalizing, any change in body language. Do this only in the routine of the day. Don't try to set up an artificial situation in which you have all things lined up to present one after the other to watch her reaction. This would not give experiential meaning to any of those items.

Even if your child, after a while, does not seem to visually recognize these items, see if she responds in anticipation to them by feel, or by sound, or to your words. It is the same thing you are trying to achieve, namely an indication of the

existence of conscious memory.

It is difficult to say how long you should continue trying to achieve signs of anticipation from your child. Non-handicapped infants anticipate familiar events by noticing all the familiar clues (e.g. the rocking chair, cuddling, and music box all precede bedtime) by the age of 6 to 9 months. Some children with severe neurological problems may never achieve this level of conscious functioning.

C. THE INFANT'S DEVELOPMENT OF BEHAVIORS THAT PRODUCE CHANGES IN HIS OR HER ENVIRONMENT

One aspect of human behavior that is true is any behavior receiving attention and praise will probably be repeated by the person receiving the praise (assuming that the person has the capacity for memory). In the same way, infants repeat and remember behavior that gets them what they want. The first time an infant does something that attracts the attention of adults, that behavior very likely was accidental. But since it created quite a response in the people around, the infant remembers and repeats it. Adults oooh and ah, or scurry to prepare the food, or change the diaper, etc. Young infants soon realize that they can make things happen by doing something to get the adults moving.

Infants with neurological impairments can be given a chance to come forth with behaviors that will produce pleasureable changes in their day. Once the anticipation level is reached (discussed in B. above), you can use the same sorts of concrete objects to allow the infant to tell you what he or she wants.

For example, suppose your child is crying. You have a pretty good idea that he wants his bottle. However, this time before giving it to him, you present him with a choice of either the bottle or the car keys. He will probably choose the bottle, and reject the car keys. Or, after you've begun running the bath water, and you see the smiles of anticipation, present your child with another choice between washcloth/soap, and a totally unrelated object. Does he look at, or hang onto the washcloth/soap, while giving the other object only brief or no attention?

By following the child's choices with the anticipated or wanted activity, you are starting a simple communication system. It is a multi-sensory input system, because you are giving your child 1) the words which go along with what he is doing (auditory), 2) the chance to learn about how the different objects feel and are used in familiar routines (tactile), 3) and the sight of these familiar items (visual). Familiar aromas and smells also help give meaning to the experiences (olfactory).

For your child to express him or herself, he or she must be able to use some kind of method of expression. Various types are speech, sign language, or use of written words. All of these are extremely complex forms of expression. On a simpler, more concrete level, a child can use objects to show a desire for some favorite activity (shows or gives you the juice cup to mean "I want some juice because I know it's snacktime now"). Also, intentional gestures of wanting something (reaching) or not wanting something (pushing it away, shaking the head) are at a very simple level of expression. Children who do not reach the level of intentional action, or conscious movement with a purpose or goal, will not be able to use a communication system.

Fortunately for children who do not have the motor abilities to use their hands, voices, or bodies to communicate with another person, today's technology allows a wide variety of modes for communication. For example, a communication device with a machine voice, can be run simply by a person puffing into a straw, lifting the little finger, or gazing in a certain direction !

Children with severe neurological impairments, including the cortically blind infant, can now have the chance to learn cause and effect (that by doing this, I make this other thing happen). This is a crucial step before communication can take place. Many toys that are battery operated are now being adapted by teachers and parents such that a child merely needs to put minimal pressure on a switch, turn their head to press a cheek plate, etc., in order to start a toy into action.

These switches can also be used in a simple object communication or choice situations (Burkhart 1982).

Below are listed some physical actions that you can help your child use so that he or she learns that (s)he has some control over everyday happenings. All of the examples listed below are **actions done by the child, and responded to by the adult.**

-Using eye gaze or eye pointing by staring at the chosen item.

-Putting hand on pressure switch to light up box containing desired item.

-Moving a "joystick" to highlight choice on an object communication array.

-Reaching toward a desired person or thing.

-Pushing away a disliked item. (Note: Children's right to say NO should be encouraged when possible. Our sense of control over our lives depends just as much on our being able to refuse).

-Nodding yes or no.

-A smile for yes, a frown for no, or any similar signals.

-An attempt by the child to continue a pleasureable adult-child body movement game by continuing part of the action.

These are just a few examples. **Be alert to any movement the child can make which, through reinforcement and praise, could be shaped into an intentional way to signal wants, choices,** and eventually conversation using a communication device if necessary.

D. MEMORY FOR THINGS AND PEOPLE NOT PRESENT

Baby sitters love to sit for infants under 9 months old because after the parents leave, the child usually remains happy. Beyond that age, their memory has developed to such an extent that they have a clear picture of mom and dad in memory, know that they have been left, and begin to wail in earnest.

The development of these internal pictures or memories is nesessary before a child can develop a conscious level of interaction with the world.

Children who are so severely damaged neurologically that they remain at an unconscious level of functioning may let the world know their needs by crying or smiling depending on their level of bodily comfort. This behavior is at the level of reflex or reaction only, and is not considered intentional for communication purposes, or goal oriented. Some children do not show even a pleasure or a pain response. These children are usually very medically fragile. One should be very careful in providing stimulation of any kind to them, and it should be done with a team approach including physical and occupational therapists, as well as medical expertise. Curriculum materials are generally hard to find at this level. Generally they involve building up the child's tolerance to carefully selected stimulation, so that startle reflexes can disappear.

The development of memory in an infant has been very well described by Jean Piaget and the many people who have interpreted his work. Most parents start to see evidence of their child's memory when the child begins to anticipate everyday events, as discussed in the anticipation section above. A parent might say "where's Daddy?" and the child looks toward the front door where Daddy was last seen disappearing.

Once the early stages of memory have developed, infants begin to pay more attention to pictures or photographs, especially of familiar people and things. This is usually after they understand the functional use of objects. For example, first you would see a 14 month old walk to the door carrying the door keys and touch them to the knob, before you would see him pay attention to a picture of keys in a book. Memory of the real experience with the object or person comes first. Once that is in place, you can use pictures for communication with the non-speaking child. Spoken words are not used by infants until they have some memory of events in their lives.

"HOW LONG DO I KEEP TRYING?"

If you have been using the above ideas consistently for 1 to 3 years and still do not see any evidence of visual or tactile recognition, or anticipation of any familiar routine events, then other programming choices should have more priority, such as good occupational and physical therapy. Maintaining good physical skills (range of motion, balance, muscle tone), and improved feeding skills are very important to the severely or profoundly handicapped child. The estimate of 1 to 3 years is a very subjective judgement. Ultimately you must rely on your own judgement and philosophical choices, since each child is unique.

Some parents have expressed dismay at the unwillingness of professionals to state with certainty whether or not there is any hope for their child to progress to higher cognitive levels. Most professionals will say that they cannot predict or make definite statements until a child is at least 3 years old. Those parents who have been most disappointed are those who have labored, under what they see as a falsely given hope, to teach their handicapped child, often at the expense of real quality time spent with the rest of the family.

If you are a parent, one of the hardest jobs is to be able to accept the possibility that your child may remain at a severely and profoundly mentally and physically handicapped level. Speaking with other parents who have been through similar experiences is often helpful. Emotional support is very important. Often, the professionals who work with you know of parent support groups in your area.

Your child, even if he or she never learns to speak, walk, or communicate by adapted methods, will always be able to respond to you at the emotional level of love, comfort, and acceptance. As humans, we place great value on our cognitive powers of thinking, judging, and analyzing. Sometimes we forget to simply be with each other and enjoy one another just as we are. Even children with severe and profound handicaps can respond on this emotional level. Even in the midst of having to deal with seizure

medications, doctors and other professionals, and hopes and fears for the future, there are times when you and your child can enjoy quality moments, which exist not in the past or future, but in the beauty of the present moment.

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